

Social care services for patients with HIV at a London teaching hospital; an evaluation

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Abstract

Objective—To investigate outpatients' use of, and satisfaction with social care services in an HIV unit.

Design—Survey of patients with HIV infection using self administered questionnaire.

Setting—Outpatient HIV clinics at the Royal Free Hospital, London, March–April 1991.

Main Outcome Measures—Patients' social circumstances, use or intended use of social care services and satisfaction with social care services.

Results—The greatest demand was for counselling about coping with HIV (38% of respondents), available medical treatment (24%), counselling for the HIV test (33%), psychological support for emotional (24%) or relationship problems (16%), advice about housing (24%) and financial matters (20%). In general, the use of social care services by men and women was similar. Twice as many men, however, sought help with payment of domestic bills, compared with women. Women were more likely to seek advice about financial benefits, obtaining sterile injecting equipment and discuss sleep and relationship problems. Thirty eight percent of patients were unemployed. Overall, 84% thought the service was good or excellent. Although less than 40% of patients currently used any one service, 60% thought they would use these services in the future.

Conclusion—The greatest demand for social care services was for coping with HIV, housing and financial matters, and HIV test counselling. More than half the patients stated that they would probably need social care services in future.

available practical support and care.³ An HIV Counselling Unit was set up in 1987 at the Royal Free Hospital, London with these objectives in order to meet the needs of the growing number of inpatients and outpatients with HIV disease.⁴

HIV counselling in the UK has its origins in a 1985 Department of Health directive⁵ to doctors stipulating that all patients undergoing testing for HIV antibodies should first be counselled about the meaning and implications of the test, and should again receive counselling upon receiving the test result. This was an opportunity for the doctor to obtain the patient's informed consent before the test, and to discuss some of the personal implications for the patient of having the test. Pre- and post HIV test counselling laid the foundations for comprehensive psychosocial care for people affected by HIV disease.⁶ The range of psychosocial care services available to patients varies between hospitals. At the Royal Free Hospital, patients can receive counselling about the test and coping with HIV disease. They can also obtain advice about financial, employment, housing and legal problems. Intravenous drug users can obtain clean injecting equipment and advice about coming off drugs. Psychological problems (such as depression and anxiety), and relationship problems are dealt with by counsellors, in collaboration with their colleagues in the Department of Psychiatry.⁴ An important question is what proportion of clinic attenders use social care services, or intend to in the future? Such information may guide planning and provision of these services. Thus, an essential part of any clinical or social care unit is to evaluate and assess the service.⁷⁻⁹ Consequently, we investigated outpatients' use of and satisfaction with the range of social care services in our HIV unit (provided by counsellors, psychologists, social workers, health advisers, a drugs team and Citizens Advice Bureau attached to the unit).

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Accepted for publication
15 July 1992

(Genitourin Med 1992;68:382-385)

Introduction

In the decade since AIDS was first described, it has been recognised that this is a complex medical problem which has profound psychosocial sequelae.¹ The psychosocial needs of patients, their contacts and family are diverse and multifaceted.² Counselling and social support services have been developed in many health care settings in order to help people make informed decisions about HIV testing, to provide psychological support for those infected with or affected by HIV, and to make

Methods

Sample

All outpatients attending one of two HIV clinics in the hospital on either a Monday or Friday over a four-week period between the 18th March and the 12th April 1991 were approached to take part in the survey. Before being seen by a doctor, they were handed a questionnaire by the clinic receptionist. It was stressed that this was an anonymous questionnaire and that we could not match any of the responses with a particular person. We

recognised that some patients may not have used the social care service and for this reason patients were also told that there were questions about their intention to use the service in the future. While the clinic receptionist did not keep a record of which patients had completed them, she attempted to avoid duplicating completion of the questionnaire by asking patients whether or not they had been given the questionnaire in a previous clinic. Patients could choose either to complete the questionnaire in the general waiting area or in a secluded area away from other patients. In order to maintain some control over the completion of the questionnaires, the clinic receptionist alone was responsible for distributing them.

The questionnaire

The self-administered six page questionnaire comprised mostly closed questions. There was one open question concerning the range of social care services available to patients and their satisfaction with them. The instrument was divided into three sections. The first covered biographical details of patients including information about their social circumstances and HIV infection (for example: "How often do you attend the hospital?" and "How do you think you were infected with HIV?"). The second section contained questions about patients' use or intended use of a range of social care services (for example: "Tick from the list of social care services those which you have used since coming to this hospital", and "Do you think you will need any of the services in this list in the future?"). The last section examined satisfaction with these services and involvement of GPs (general practitioners) in patients' care (for example: "How would you rate the social care service offered to you?" and "Does your GP know that you have HIV infection?").

Data analysis

Data were coded and analysed using SAS-PC. Because this was a descriptive study not testing any formal hypotheses, we analysed the results without conducting any formal statistical tests.

Results

Sample profile

During the four-week period of the study 170 patients (141 men, 29 women) attended the eight outpatient clinics (two clinics per week).

Questionnaires were completed by 152 people, representing a response rate of 89%. All of the sample were HIV-infected patients attending for follow-up care in the HIV Outpatient Clinic at the Royal Free Hospital. The majority of the respondents (123) were males; 24 women completed questionnaires while five respondents did not indicate their sex. The median age was 32 years and the range was from 20 to 62 years (70% were between 25 and 45). A quarter of the sample (36) had come to live in the UK within the last five years.

We asked patients what they considered to have been their primary behavioural risk for HIV infection. Eighty percent of the men in the survey said that they believed that sexual contact with someone of the same sex had resulted in infection (see table 1).

A third of the sample (37%) were relatively new to the HIV care service at the Royal Free Hospital, having been registered in the previous six months. A further 23% had been registered at the Hospital for between six months and a year. The remaining 40% were patients who had been attending for HIV care for a year or longer. The majority of patients in the sample (84%) attended the hospital for HIV care at least once a month, and of these, 26% (40 patients) were seen in outpatient clinics either once a week or once a fortnight. The remainder were seen at intervals of between six and twelve weeks, while 4% of the sample attended only when they felt they needed to be seen by a doctor.

The sample was almost equally divided between those in or out of work: 62 (41%) were employed, 57 (38%) were unemployed, 11 (7%) were students, and 20 (14%) stated other categories or circumstances (for example: a refugee and not permitted to work until legal matters sorted out). We did not have information on employment for two patients. Of those who attended once a month or more, 40% were unemployed, compared with 19% of those attending less frequently. It is likely that the higher level of unemployment in frequent attenders reflects their poorer state of health (table 2).

Most patients either owned their own home (34%) or rented from a private landlord (32%). Of the remainder, 17% rented from the local council and 10% rented from a housing association. A further 5% were homeless and 2% lived in bed and breakfast accommodation. Three patients did not indicate where they lived.

Table 1 Route of infection with HIV, by sex

<i>Primary risk</i>	<i>Male</i>	<i>Female</i>	<i>Total* (%)</i>
Via a blood transfusion in this country	1	0	1 (1)
Via a blood transfusion abroad	3	0	4 (3)
Sexual contact with someone of the same sex	99	0	102 (68)
Sexual contact with someone of the opposite sex	8	14	22 (15)
Sexual contact with an intravenous drug user	0	1	1 (1)
Sharing needles with an intravenous drug user	2	2	4 (3)
Other	3	1	4 (3)
Don't know	5	5	11 (7)
	120	24	149 (100)

*Total includes 5 people for whom sex was not recorded.
(Data on route of infection missing for three patients).

Table 2 Frequency of attendance in relation to employment status of HIV outpatients* (% in brackets)

	Every 1-2 weeks	Every 3-4 weeks	> 4 weeks	Total
Employed	14 (36)	33 (38)	10 (63)	57 (40)
Student	3 (8)	7 (3)	1 (6)	11 (8)
Unemployed	16 (41)	34 (40)	3 (19)	53 (38)
Other	6 (15)	12 (14)	2 (12)	20 (14)
	39 (100)	86 (100)	16 (100)	141 (100)

*Data missing for 11 patients.

Use of social care services

We had information from 147 patients on their use of HIV social care services in the hospital. These services were categorised into practical needs, personal and emotional problems, and counselling about HIV (table 3).

The percentage of patients using any one service ranged from 1% (free condoms and detoxification prescriptions for drug users) to 38% (coping with HIV). Approximately one third of patients had received counselling about the HIV test. A quarter of the sample had sought counselling about medical treatments, psychological support for depression and anxiety, and advice about housing and financial benefits. Relationship and family problems, information about safer sex and injecting drug use, advice about mobility allowance and sleep problems have prompted patients to seek professional help from members of the social care team in 10% of cases. A smaller proportion have obtained sterile drug injecting equipment from the team and sought help with employment, obtaining household appliances and furniture, legal problems, immigration matters, sexual problems, relaxation training and coming off drugs.

Use of social care services by men and women was broadly similar. Twice as many men, however, have sought help with regard to the payment of domestic bills as women. On the other hand, more women than men approached the social care team requesting advice about particular financial benefits (for

example, child support allowances), obtaining sterile drug injecting equipment, help with sleep and relationship problems and counselling about safer sex and drug use. There was little variation in the use of social care services by age and frequency of attendance at the clinic (data available from authors on request).

View of service provided

Over half of the sample (60%) said that they thought they would need some of the services listed above in the future. Thirty-five percent did not know whether they would use the services while 5% said they did not intend to use any of the services in the future. Information on this question was not provided by two patients. Of those who had used these services in the past, 51% rated it as excellent, 33% as good, 14% as average, while 2% thought that it was poor or very poor. (There was no information from 19 patients.)

Involvement of general practitioner

The majority of our patients (83%) with HIV are registered with a GP. Seventeen percent stated that they were not (eight patients did not answer this question). Of the 119 patients registered with a GP, 68 (57%) have told their GP their HIV diagnosis. The remainder had not done so and were unaware as to whether their GP knew about their HIV seropositivity.

Table 3 Number of patients, by sex, indicating whether they have ever used different social care services (% in brackets)

	Male (n = 123)	Female (n = 24)	Total (n = 147)
<i>Practical needs</i>			
Employment Advice	9 (7)	2 (8)	11 (7)
Housing	28 (23)	7 (29)	35 (24)
Mobility Allowance	6 (7)	7 (8)	12 (9)
Income Support	24 (20)	6 (25)	30 (20)
Payment of Bills	16 (13)	2 (8)	18 (12)
Other financial benefits	11 (9)	3 (13)	14 (10)
Furniture/household appliances	5 (4)	2 (8)	7 (5)
Legal problems	8 (7)	1 (4)	9 (6)
Immigration/visas	8 (7)	2 (8)	10 (7)
Free condoms	2 (2)	0 (0)	2 (1)
Sterile needles/works	9 (7)	3 (13)	12 (8)
Detoxification prescriptions	0 (0)	1 (4)	1 (1)
<i>Personal Issues</i>			
Depression or anxiety	29 (24)	6 (25)	35 (24)
Sleeping problems	10 (8)	6 (25)	16 (11)
Sexual problems	7 (6)	1 (4)	8 (5)
Family/relationship problems	18 (15)	5 (21)	23 (16)
Relaxation training	7 (6)	1 (4)	8 (5)
Coming off drugs	3 (2)	1 (4)	4 (3)
<i>Counselling about HIV</i>			
The HIV test	40 (33)	9 (38)	49 (33)
Coping with HIV	45 (37)	11 (46)	56 (38)
Safer sex/drug use	14 (11)	5 (21)	19 (13)
Medical treatments	31 (25)	4 (17)	35 (24)

(Patients could use more than one service).

Discussion

Although the range of social care services at the Royal Free Hospital on offer to patients is broad and extends into practical help, offering guidance and advice and psychological counselling, it is clear from this survey that some of these are used more than others. The greatest demand from patients was in relation to counselling about coping with HIV, medical treatments available, counselling for the HIV test, psychological support for emotional and relationship problems, and advice about housing and financial matters. The diversity of need is consistent with a previous national survey of social care services for people with HIV disease.² Overall the need for any one service is relatively small. The highest demand was for counselling about coping with HIV, yet only 38% of the sample had approached the social care team for this particular service. Some patients may receive help and support from their family and community-based services such as the Terrence Higgins Trust and Body Positive.

We did not have information about the reasons for unemployment among the survey sample, but it is noteworthy that there was a high level of unemployment (38%) even among the less frequent attenders. A proportion of the unemployed patients were possibly too unwell to work. Other patients may have felt that they were becoming unwell and therefore did not want to continue working. Some may have been discriminated against because of their HIV status or may have been out of work before receiving their positive HIV test result, although we do not have data to confirm this. The high level of unemployment has implications for the provision of social care services. These patients may need more help in obtaining financial and housing benefits than other patients. Furthermore, unemployment may adversely affect their psychological state and exacerbate symptoms associated with adjustment to terminal illness.

Our data show that attempts to involve GPs more closely in HIV care¹⁰ have only been partially successful. Over half our sample had discussed their diagnosis with their GP. The remainder had not. A reluctance to disclose the diagnosis to the GP may arise from a fear of prejudice or a concern that life insurance companies may penalize HIV infected patients. The trend towards providing comprehensive clinical and social care in the hospital to patients with HIV¹¹ may, in the minds of some patients, circumvent the need for a GP. There is a case for counselling patients about the pros and cons of telling their GP their diagnosis because there are also some advantages for the patient in their GP knowing the diagnosis. Certain treatments can be administered to patients at home while for some patients, terminal care at home can be provided by GPs.

One of the limitations of this study was that we did not draw a random sample of patients who were being treated at the Royal Free Hospital for HIV care. The survey sample comprised outpatients attending between

March and April 1991. Since the majority of these patients (84%) attended the hospital at least once a month, it is reasonable to assume that many in the sample were quite unwell with greater need of medical and social support services. Thus, outpatients who were unwell and attending frequently were over represented in the study.

Of those who were included in the survey, 84% thought that the social care service was either good or excellent. However, those who were dissatisfied with the service may have found support and counselling elsewhere and so did not attend for social care in the hospital. The overall level of satisfaction with the social care services at the Royal Free Hospital compares favourably with the national survey of HIV social care services in which 53 out of 181 patients said that they found at least one aspect of social care services to be helpful.² In keeping with current national trends, our service may treat a larger number of women and paediatric HIV cases in the future, and demand for services may shift in response to the changing profile of patients treated. In turn, new initiatives in the social care team will need to be developed in order to meet these needs.

Conclusion

The main areas of social support provided by the hospital and being used by patients are counselling about HIV and coping with the diagnosis, support for those experiencing psychological and relationship problems and advice about housing and financial matters. Of those patients using these services at present, the majority gave a positive evaluation of them. More than half the patients stated that they would probably need social care services in future. These services will need to develop according to the needs of our patients.

We are grateful to Olia Papacosta MSc, Research Statistician in the Department of General Practice and Primary Care, Royal Free Hospital School of Medicine, London, who helped with the analysis of the data.

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